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Maternal, Infant, and Child Health

Co-Lead Agencies: Centers for Disease Control and Prevention;
Health Resources and Services Administration

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Goal

Improve the health and well-being of women, infants, children, and families.

Overview

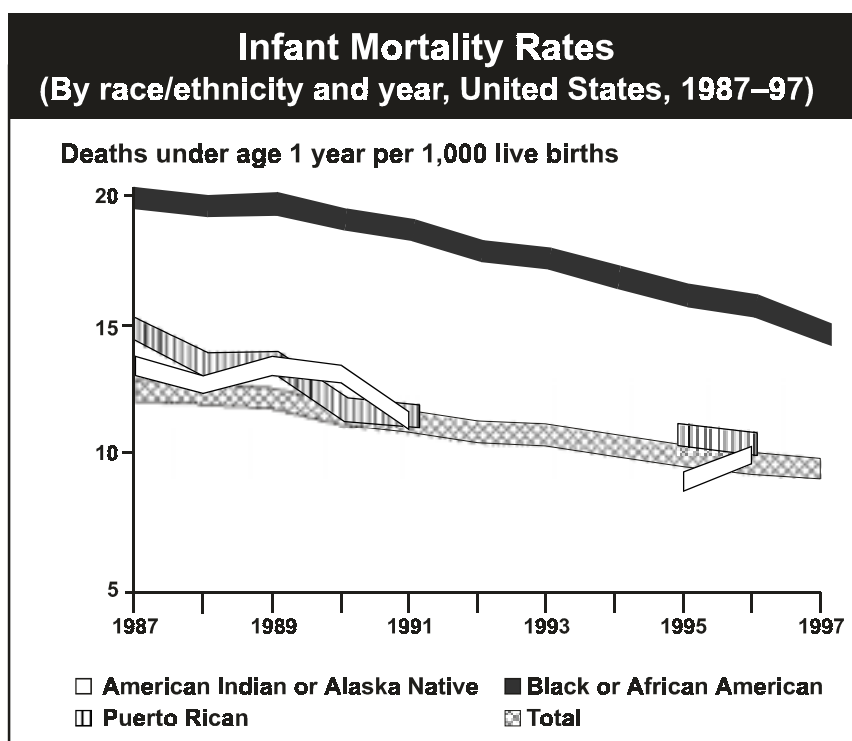
The health of mothers, infants, and children is of critical importance, both as a reflection of the current health status of a large segment of the U.S. population and as a predictor of the health of the next generation. This focus area addresses a range of indicators of maternal, infant, and child health—those primarily affecting pregnant and postpartum women (including indicators of maternal illness and death and preconceptional health) and those that affect infants' health and survival (including infant death; birth outcomes; prevention of birth defects; access to preventive care; and fetal, perinatal, and infant deaths).

Infant death is an important measure of a nation's health and a worldwide indicator of health status and social well-being. As of 1995, the U.S. infant mortality rates ranked 25th among industrialized nations.¹ In the past decade, critical measures of increased risk of infant death, such as new cases of low birth weight (LBW) and very low birth weight (VLBW), have actually increased in the United States. In addition, the disparity in infant mortality rates between whites and specific racial and ethnic groups (especially African Americans, American Indians or Alaska Natives, Native Hawaiians, and Puerto Ricans) persists. Although the overall infant mortality rate has reached record low levels, the rate for African Americans remains twice that of whites.²

Issues and Trends

In 1997, 28,045 infants died before their first birthday, for an overall rate of 7.2 deaths per 1,000 live births. This rate has declined steadily over the past 20 years; in 1975, the infant mortality rate was over 15 per 1,000 live births.² In 1996, nearly two-thirds of all infant deaths took place during the first 28 days of life (the neonatal period). The overall neonatal mortality rate in 1997 was 4.8 per 1,000 live births.² The remaining one-third of infant deaths took place during the post-neonatal period from an infant's 29th day of life until the first birthday. The U.S. postneonatal mortality rate in 1997 was 2.4 deaths per 1,000 live births.²

Four causes account for more than half of all infant deaths: birth defects, disorders relating to short gestation and unspecified LBW, sudden infant death syndrome (SIDS), and respiratory distress syndrome. The leading causes of neonatal death in 1997 were birth defects, disorders related to short gestation and LBW, respiratory distress syndrome, and maternal complications of pregnancy. After the first month of life, SIDS is the leading cause of infant death, accounting for about one-third of all deaths during this period. Maternal age also is a risk factor for infant death.



Source: National Vital Statistics System (NVSS), CDC, NCHS. Data for 1997 are preliminary; 1992-94 data for American Indian or Alaska Native and Puerto Rican are not available; 1987-91 data for Puerto Rican are for selected States.

Mortality rates are highest among infants born to young teenagers (16 years and under) and to mothers aged 44 years and older.

The death of fetuses before birth is another important indicator of perinatal health. In 1996, nearly 7 fetal deaths were reported for every 1,000 live births and fetal deaths combined, representing a slight decline from the fetal mortality rate of 7.6 per 1,000 in 1987.² Fetal death sometimes is associated with pregnancies complicated by such risk factors as problems with amniotic fluid levels and maternal blood disorders.³ Early, comprehensive, and risk-appropriate care to manage such conditions has contributed to reductions in fetal mortality rates.

Short gestation and LBW are among the leading causes of neonatal death, accounting for 20 percent of neonatal deaths. In 1997, a total of 11.4 percent of births were preterm, and 7.5 percent were of LBW.⁴ Included in these statistics were infants born at VLBW, or less than 1,500 grams (3.3 pounds). The rate of VLBW births was 1.4 percent in 1997. The VLBW rate has increased slightly since 1990 among whites and other population groups including African Americans, Puerto Ricans, and American Indians.

LBW is associated with long-term disabilities, such as cerebral palsy, autism, mental retardation, vision and hearing impairments, and other developmental dis-

abilities. (See Focus Area 6. Disability and Secondary Conditions and Focus Area 28. Vision and Hearing.) Despite the low proportion of pregnancies resulting in LBW babies, expenditures for the care of LBW infants total more than half of the costs incurred for all newborns. In 1988, the cost of a normal, healthy delivery averaged \$1,900, whereas hospital costs for LBW infants averaged \$6,200.⁵

The general category of LBW infants includes both those born too early (preterm infants) and those who are born at full term but who are too small, a condition known as intrauterine growth retardation (IUGR). Maternal characteristics that are risk factors associated with IUGR include maternal LBW, prior LBW birth history, low prepregnancy weight, cigarette smoking, multiple births, and low pregnancy weight gain. Cigarette smoking is the greatest known risk factor.⁶

VLBW usually is associated with preterm birth. Relatively little is known about risk factors for preterm birth, but the primary risk factors are prior preterm birth and spontaneous abortion, low prepregnancy weight, and cigarette smoking.⁵ These risk factors account for only one-third of all preterm births. Maternal use of illicit drugs also may increase the risk of VLBW.

The use of alcohol, tobacco, and illegal substances during pregnancy is a major risk factor for LBW and other poor infant outcomes. Alcohol use is linked to fetal death, LBW, growth abnormalities, mental retardation, and fetal alcohol syndrome (FAS).⁷ Overall rates of alcohol use during pregnancy have increased during the 1990s, and the proportion of pregnant women using alcohol at higher and more hazardous levels has increased substantially. Smoking during pregnancy is linked to LBW, preterm delivery, SIDS, and respiratory problems in newborns. In addition to the human cost of these conditions, the economic cost of services to substance-exposed infants is great: Health expenditures related to FAS are estimated to be from \$75 million to \$9.7 billion each year.⁷ Over \$500 million a year is spent on medical expenses for infants exposed to cocaine in utero.⁸ Smoking-attributable costs of complicated births in 1995 were estimated at \$1.4 billion (11 percent of costs for all complicated births, based on smoking prevalence during pregnancy of 19 percent) and \$2.0 billion (15 percent for all complicated births, based on smoking prevalence during pregnancy of 27 percent).⁹

Finally, breastfeeding is an important contributor to overall infant health, as human breast milk presents the most complete form of nutrition for infants.¹⁰ (The American Academy of Pediatrics recommends that women who test positive for HIV not breastfeed to help prevent transmission of the virus to their infants.)¹¹ Breastfeeding rates have increased over the years, particularly in early infancy. However, breastfeeding rates among women of all races decrease substantially by 5 to 6 months postpartum. The 1997 rates at 5 to 6 months were only 29 percent among white women, 14.5 percent among African American women, and 24.5 percent among Hispanic women.¹²

Also important to child health are the prevention and treatment of disabilities in children. Twelve percent of all children aged 18 years and under have a disability

(defined as a limitation in one or more functional areas). In 1994, 10.6 percent of all children aged 5 to 17 years had limitations in learning ability, 6 percent had limitations in communication, 1.3 percent had limitations in mobility, and 0.9 percent had limitations in personal care.¹³ The burden of childhood disability is compounded because affected children live with their disabling conditions many more years than do persons acquiring disability later in life. In 1992, asthma and mental retardation were the most common disabling conditions, accounting for 40 percent of all activity limitations.¹⁴ Other major disabling conditions in childhood include speech impairment, hearing impairment, cerebral palsy, epilepsy, and leg impairment. (See Focus Area 6. Disability and Secondary Conditions and Focus Area 28. Vision and Hearing.)

The objectives in this focus area cover the broad array of childhood conditions and genetic disorders. An example of preventable birth defects is spina bifida and other neural tube defects (NTDs). The occurrence of these disorders could be reduced by more than half if women consumed adequate folic acid before and during pregnancy.

All States require newborns to be screened for genetic conditions, such as phenylketonuria (PKU) and hypothyroidism; the majority of States also require screening for sickle cell disease. Although not necessarily preventable, these conditions are susceptible to intervention after delivery. For example, nutritional interventions in infancy can prevent mental retardation in children with PKU, penicillin can prevent infection in children with sickle cell disease, and hormone replacement can prevent mental retardation in children with hypothyroidism. Thus, adequate screening of newborns is the first step toward prevention of illness, disability, and death.

In addition to infant deaths and health conditions, the effect of pregnancy and childbirth on women is an important indicator of women's health. In 1997, a total of 327 maternal deaths were reported by vital statistics.¹⁵ While this number is small, maternal death remains significant because a high proportion of these deaths are preventable and because of the impact of women's premature death on families. The maternal mortality ratio among African American women consistently has been three to four times that of white women. Ectopic pregnancy is an important cause of pregnancy-related illness and disability in the United States and the leading cause of maternal death in the first trimester. The risk of ectopic pregnancy increases with age; women of all races aged 35 to 44 years are at more than three times the risk of ectopic pregnancy than are women aged 15 to 24 years.¹⁶ Preeclampsia and eclampsia make up the second leading cause of pregnancy-related death. Other causes of maternal death are hemorrhage, embolism, infection, and anesthesia-related complications.

The rates of many of these indicators have shown improvement over the past decade. The rate of infant mortality declined more than 27 percent between 1987 and 1996. The rate of fetal mortality declined 8 percent between 1987 and 1995. Other

indicators show less progress. The LBW rate increased 8.7 percent between 1987 and 1997. The rate of FAS has risen steeply, especially among African Americans. In addition, the maternal mortality rate has not declined since 1982, nor has the disparity between African American and white women.

Despite these unfavorable trends, evidence is encouraging about increases in women's use of health practices that can help their own health and that of their infants. The percentage of pregnant women who start prenatal care early increased 8.5 percent between 1987 and 1996. The percentage of mothers who breastfeed their newborns also went up 15.5 percent between 1988 and 1997, with greater gains among African American and Hispanic women. Other maternal health practices have shown less improvement: in 1992-94, the proportion of women of childbearing age reporting consumption of the recommended level of folic acid (400 micrograms) was 21 percent.

Disparities

Many of these conditions and risk factors disproportionately affect certain racial and ethnic groups. The disparities between white and nonwhite groups in infant death, maternal death, and LBW are wide and, in many cases, are growing. Specifically:

- The 1996 infant mortality rate among African American infants was 2.4 times that of white infants. Although infant mortality rates have declined within both racial groups, the proportional discrepancy between African Americans and whites remains largely unchanged.²
- The rate of maternal mortality among African Americans is 20.3 per 100,000 live births, nearly four times the white rate of 5.1 per 100,000, although the rate among African Americans has been declining over the years. African American women continue to be three to four times more likely than white women to die of pregnancy and its complications. The maternal death differential between African Americans and whites is highest for pregnancies that did not end in live birth (ectopic pregnancy, spontaneous and induced abortions, and gestational trophoblastic disease).¹⁷
- Rates of LBW for white women have risen from 5.7 percent of births in 1990 to 6.5 percent in 1997. Among African Americans, the LBW rate has declined slightly in the 1990s but remains twice as high as that of whites—13 percent in 1997. African Americans also are more likely to have other risk factors, such as young maternal age, high birth order (that is, having many live births), less education, and inadequate prenatal care. Puerto Ricans also are especially likely to have LBW infants.⁴
- American Indians or Alaska Natives and African Americans account for a disproportionate share of FAS deaths. In 1990, the rates of FAS among

American Indians or Alaska Natives and African Americans were 5.2 and 1.4 per 1,000 live births, respectively, compared with 0.4 per 1,000 among the population as a whole.¹⁸

African American and Hispanic women also are less likely than whites to enter prenatal care early. For both African American and white women, the proportion entering prenatal care in the first trimester rises with maternal age until the late thirties, then begins to decline. For example, in 1997, 56.6 percent of African American women aged 18 years and under began care early, compared with 66.2 percent of white women of the same age. Among women aged 25 to 39 years, 77.6 percent of African American women entered care early, compared with 87.7 percent of white women.⁴

Women in certain racial and ethnic groups also are less likely than white women to breastfeed their infants. In the early postpartum period, 41.3 percent of African American mothers and 63.6 percent of Hispanic mothers breastfed in 1997, compared with 66.5 percent of white women. These differences persist at 5 to 6 months postpartum, when 14.5 percent of African American women, 24.5 percent of Hispanic women, and 28.6 percent of white women breastfed.¹²

Opportunities

Many of the risk factors mentioned can be mitigated or prevented with good preconception and prenatal care. First, preconception screening and counseling offer an opportunity to identify and mitigate maternal risk factors before pregnancy begins. Examples include daily folic acid consumption (a protective factor) and alcohol use (a risk factor). During preconceptional counseling, healthcare providers also can refer women for medical and psychosocial or support services for any risk factors identified. Counseling needs to be culturally competent and linguistically appropriate. Prenatal visits offer an opportunity to provide information about the adverse effects of substance use, including alcohol and tobacco during pregnancy, and provide a vehicle for referrals to treatment services. The use of timely, high-quality prenatal care can help to prevent poor birth outcomes and improve maternal health by identifying women who are at particularly high risk and taking steps to mitigate risks, such as the risk of high blood pressure or other maternal complications. Interventions targeted at prevention and cessation of substance use during pregnancy may be helpful in further reducing the rate of VLBW infants. Further promotion of folic acid intake can help to reduce the rate of NTDs.

Other actions taken after birth can significantly improve infants' health and chances of survival. Breastfeeding has been shown to reduce rates of infection in infants and to improve maternal health.^{19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32} SIDS may be preventable as well: studies show that putting infants to sleep on their backs can help to prevent SIDS.³³

Interim Progress Toward Year 2000 Objectives

Of the 17 maternal and infant health objectives included in Healthy People 2000, progress has been made toward the target in 8 objectives, and the movement has been away from the target in 5 objectives. Notable gains have been made in the areas of infant death, fetal death, cesarean delivery (particularly repeat cesareans), breastfeeding, early use of prenatal care, hospitalization for complications of pregnancy, abstinence from tobacco use during pregnancy, and screening for fetal abnormalities and genetic disorders. However, no progress or movement in the wrong direction has occurred in the areas of maternal death, FAS, and LBW. For the other objectives, there has been mixed progress, or data remain unavailable. Child health objectives were not included in the Maternal and Infant focus area in Healthy People 2000.

Note: Unless otherwise noted, data from Centers for Disease Control and Prevention, National Center for Health Statistics, *Healthy People 2000 Review, 1998-1999*.

Maternal, Infant, and Child Health

Goal: Improve the health and well-being of women, infants, children, and families.

Number Objective

Fetal, Infant, and Child Deaths

- 16-1 Fetal and infant deaths
- 16-2 Child deaths
- 16-3 Adolescent and young adult deaths

Maternal Death and Illness

- 16-4 Maternal deaths
- 16-5 Maternal illness and complications due to pregnancy

Prenatal Care

- 16-6 Prenatal care
- 16-7 Childbirth classes

Obstetrical Care

- 16-8 Very low birth weight infants born at Level III hospitals
- 16-9 Cesarean deliveries

Risk Factors

- 16-10 Low birth weight and very low birth weight
- 16-11 Preterm birth
- 16-12 Weight gain during pregnancy
- 16-13 Infants put to sleep on their backs

Developmental Disabilities and Neural Tube Defects

- 16-14 Developmental disabilities
- 16-15 Spina bifida and other neural tube defects
- 16-16 Optimum folic acid

Prenatal Substance Exposure

- 16-17 Prenatal substance exposure
- 16-18 Fetal alcohol syndrome

Breastfeeding, Newborn Screening, and Service Systems

- 16-19 Breastfeeding
- 16-20 Newborn bloodspot screening
- 16-21 Sepsis among infants with sickle cell disease
- 16-22 Medical home for children with special health care needs
- 16-23 Service systems for children with special health care needs

Healthy People 2010 Objectives

Fetal, Infant, and Child Deaths

16-1. Reduce fetal and infant deaths.

Target and baseline:

Objective	Reduction in Fetal and Infant Deaths	1997 Baseline	2010 Target
		Per 1,000 Live Births Plus Fetal Deaths	
16-1a.	At 20 or more weeks of gestation	6.8	4.1
16-1b.	During perinatal period (28 weeks of gestation to 7 days or more after birth)	7.5	4.5

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births Plus Fetal Deaths, 1997 (unless noted)	16-1a. Death at 20 or More Weeks of Gestation	16-1b. Death During Perinatal Period
	Rate per 1,000	
TOTAL	6.8	7.5
Mother's race and ethnicity		
American Indian or Alaska Native	6.7	7.9
Asian or Pacific Islander	4.8	4.6
Asian	4.2	4.6
Native Hawaiian and other Pacific Islander	6.2	7.3
Black or African American	12.5	13.4
White	5.8	6.4
Hispanic or Latino	5.9	6.5
Not Hispanic or Latino	DNA	7.2
Black or African American	9.6	12.7
White	5.2	6.0

Live Births Plus Fetal Deaths, 1997 (unless noted)	16-1a. Death at 20 or More Weeks of Gestation	16-1b. Death During Perinatal Period
	Rate per 1,000	
Gender		
Female	DNA	DNA
Male	DNA	DNA
Mother's age		
Under 15 years	14.2	DNA
15 to 19 years	7.8	DNA
20 to 24 years	6.4	DNA
25 to 29 years	6.0	DNA
30 to 34 years	6.3	DNA
35 years and older	8.9	DNA
Mother's education level		
Less than high school	6.5	DNA
High school graduate	6.7	DNA
At least some college	4.8	DNA
Fetal weight		
> 2,499g	1.3	DNA
1,500 to 2,499g	16.8	DNA
< 1,500g	213.1	DNA
Mother's disability status		
Mothers with disabilities	DNC	DNC
Mothers without disabilities	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

Target and baseline:

Objective	Reduction in Infant Deaths	1998 Baseline*	2010 Target
		Rate per 1,000 Live Births	
16-1c.	All infant deaths (within 1 year)	7.2	4.5
16-1d.	Neonatal deaths (within the first 28 days of life)	4.8	2.9
16-1e.	Postneonatal deaths (between 28 days and 1 year)	2.4	1.5

*Preliminary data

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births, 1997*	16-1c. All Infant Deaths (< 1 year)	16-1d. Neonatal Deaths (< 28 days)	16-1e. Postneonatal Deaths (28 to 364 days)
Rate per 1,000			
TOTAL	7.2	4.8	2.5
Mother's race and ethnicity			
American Indian or Alaska Na- tive	8.7	4.5	4.2
Asian or Pacific Islander	5.0	3.2	1.8
Asian	4.6	3.0	1.6
Native Hawaiian and other Pacific Islander	7.9	5.1	2.8
Black or African American	13.7	9.2	4.5
White	6.0	4.0	2.1
Hispanic or Latino	6.0	4.0	2.0
Not Hispanic or Latino	7.4	4.9	2.5
Black or African American	13.7	9.4	4.5
White	6.0	3.9	2.1
Gender			
Female	6.5	4.3	2.1
Male	7.9	5.2	2.7
Mother's age			
Under 15 years	19.0	12.4	6.6
15 to 19 years	10.3	6.2	4.1
20 to 24 years	8.0	4.9	3.2
25 to 29 years	6.2	4.3	1.9
30 to 34 years	5.8	4.2	1.6
35 years and older	7.1	5.2	2.0
Mother's education level			
Less than high school	9.2	5.3	4.0
High school graduate	7.6	5.0	2.6
At least some college	5.3	3.7	1.5

Live Births, 1997*	16-1c. All Infant Deaths (< 1 year)	16-1d. Neonatal Deaths (< 28 days)	16-1e. Postneonatal Deaths (28 to 364 days)
Rate per 1,000			
Infant birth weight			
> 2,499g	2.7	1.0	1.7
1,500 to 2,499g	16.7	9.5	7.2
< 1,500g	252.8	223.8	29.0
Mother's disability status			
Mothers with disabilities	DNC	DNC	DNC
Mothers without disabilities	DNC	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

*New data for population groups will be added when available.

Target and baseline:

Objective	Reduction in Infant Deaths Related to Birth Defects	1998 Baseline* (unless noted)	2010 Target
		Rate per 1,000 Live Births	
16-1f.	All birth defects	1.6	1.1
16-1g.	Congenital heart defects	0.54 (1997)	0.38

*Preliminary data

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births, 1997* (unless noted)	16-1f. All Infant Deaths From All Birth Defects	16-1g. All Infant Deaths From Congenital Heart Defects
Rate per 1,000		
TOTAL	1.6	0.54
Mother's race and ethnicity		
American Indian or Alaska Native	1.7	0.62
Asian or Pacific Islander	1.4	0.47

Live Births, 1997* (unless noted)	16-1f. All Infant Deaths From All Birth Defects	16-1g. All Infant Deaths From Congenital Heart Defects
	Rate per 1,000	
Asian	1.2	0.39
Native Hawaiian and other Pacific Islander	DSU	DSU
Black or African American	1.8	0.59
White	1.6	0.53
Hispanic or Latino	1.7	0.53
Not Hispanic or Latino	1.6	0.54
Black or African American	1.8	0.60
White	1.5	0.53
Gender		
Female	1.6 (1995)	DNA
Male	1.8 (1995)	DNA
Mother's education level		
Less than high school	2.1	0.59
High school graduate	1.7	0.61
At least some college	1.3	0.45
Disability status (of infant)		
Persons with disabilities	DNC	DNC
Persons without disabilities	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

*New data for population groups will be added when available.

16-1h. Reduce deaths from sudden infant death syndrome (SIDS).

Target: 0.30 deaths per 1,000 live births.

Baseline: 0.77 deaths per 1,000 live births were from SIDS in 1997.

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births, 1997	SIDS Deaths Rate per 1,000
TOTAL	0.77
Mother's race and ethnicity	
American Indian or Alaska Native	1.56
Asian or Pacific Islander	0.51
Asian	0.45
Native Hawaiian and other Pacific Islander	DSU
Black or African American	1.43
White	0.65
Hispanic or Latino	0.47
Not Hispanic or Latino	0.85
Black or African American	1.46
White	0.71
Gender	
Female	DNA
Male	DNA
Mother's education level	
Less than high school	1.48
High school graduate	0.90
At least some college	0.41
Disability status (of infant)	
Persons with disabilities	DNC
Persons without disabilities	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

Infant death is a critical indicator of the health of a population. It reflects the overall state of maternal health, as well as the quality and accessibility of primary health care available to pregnant women and infants. Despite steady declines in the 1980s and 1990s, the rate of infant mortality in the United States remains among the highest in the industrialized world.¹ Moreover, the rate of decline in infant mortality has slowed since the 1970s, when major advances in neonatal care contributed to steep reductions in the neonatal mortality rate. However, the rapid decline in this rate slowed during the 1980s. In the early 1990s, the introduction of synthetic surfactant contributed to declines in neonatal mortality rates through decreased new cases of intraventricular hemorrhage and decreased severity of respiratory disease in preterm, very small infants.^{33, 34}

The health of infants depends in large part on their health in utero. A fetus with severe defects or growth problems may not be delivered alive. Because only live births are counted in infant mortality rates, perinatal and fetal mortality rates provide a more complete picture of perinatal health than does the infant mortality rate alone.

Fetal death often is associated with maternal complications of pregnancy, such as problems with amniotic fluid levels and blood disorders. Rates of fetal mortality are 35 percent greater than average in women who use tobacco during pregnancy and 77 percent higher in women who use alcohol.³ Fetal mortality rates also are high when birth defects, such as anencephalus, renal agenesis, and hydrocephalus, are present.³ The baseline fetal mortality rate of 7 per 1,000 represents only a 6.7 percent reduction since 1990, an average rate of decline of 1.3 percent per year. The fetal mortality rate among African Americans was 12.7 per 1,000 in 1995, 1.8 times that of the population as a whole. Moreover, this gap has widened since 1990. The rate among African Americans declined by only 4.5 percent over this period, a decline of less than 1 percent per year.³ Targeting prenatal risk screening and intervention to high-risk groups, particularly African American women, is critical to reducing this gap.

The perinatal mortality rate includes both deaths of live-born infants through the first 7 days of life and fetal deaths after 28 weeks of gestation. This rate includes both deaths of live-born infants and fetal deaths and is a useful overall measure of perinatal health and the quality of health care provided to pregnant women and newborns. The rate of perinatal mortality has declined by 40 percent since 1980. The gap between African Americans and whites has increased, however, with the rate among African Americans now more than twice that of whites.

The infant mortality rate is made up of two components: neonatal mortality (death in the first 28 days of life) and postnatal mortality (death after the first month but within the first year). The leading causes of neonatal death include birth defects, disorders related to short gestation and LBW, and pregnancy complications. Of these, the most likely to be preventable are those related to preterm birth and LBW, which represent approximately 20 percent of neonatal deaths. Postneonatal death reflects events experienced in infancy, including SIDS, birth defects, injuries, and homicide. Birth defects, many of which are unlikely to be preventable given current scientific knowledge, account for approximately 17 percent of postneonatal deaths; the remainder are likely to stem from preventable causes. SIDS is the leading cause of postneonatal death among all racial and ethnic groups, representing nearly one-third of all cases of postneonatal death. Moreover, the rate of SIDS among African Americans is 1.6 per 1,000 live births, twice that of whites. Therefore, a reduction in the rate of death from SIDS, particularly among African Americans, would contribute greatly to reducing the overall infant mortality rate and particularly to closing the racial gap in postneonatal death. The 2010 target should be achievable with continued education. (See objective 16-13 for further discussion of interventions that can help to prevent SIDS).

Rates of death from birth defects can be reduced either by preventing the occurrence of the defect itself or by providing the necessary care to prevent death. In the case of NTDs, the birth defects themselves can be prevented (see objectives 16-17 and 16-18). Death from birth defects that are not so easily prevented, such as heart problems, can be reduced with access to appropriate medical care. (Respiratory distress syndrome, another leading cause of infant death, is not a birth defect but a consequence of prematurity.)

A particular issue in the reduction of infant death is the reduction of disparities among select populations, particularly as defined by race and ethnicity, maternal age, and infant birth weight. The gap between whites and African Americans in infant death is large and has not diminished.

16-2. Reduce the rate of child death.

Target and baseline:

Objective	Reduction in Deaths of Children	1998 Baseline* (unless noted)	2010 Target
		Rate per 100,000	
16-2a.	Children aged 1 to 4 years	34.2	25.0
16-2b.	Children aged 5 to 9 years	17.6	14.3

*Preliminary data

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Children, 1997*	16-2a. Deaths of Children Aged 1 to 4 Years	16-2b. Deaths of Children Aged 5 to 9 Years
	Rate per 100,000	
TOTAL	35.8	18.5
Mother's race and ethnicity		
American Indian or Alaska Native	59.1	27.0
Asian or Pacific Islander	25.1	14.4
Asian	DNC	DNC
Native Hawaiian and other Pacific Islander	DNC	DNC
Black or African American	59.2	30.1
White	31.6	16.2

Children, 1997*	16-2a. Deaths of Children Aged 1 to 4 Years	16-2b. Deaths of Children Aged 5 to 9 Years
	Rate per 100,000	
Hispanic or Latino	31.3	15.6
Not Hispanic or Latino	36.6	18.9
Black or African American	61.8	31.4
White	31.1	16.0
Gender		
Female	31.8	16.6
Male	39.8	20.2
Family income level		
Poor	DNC	DNC
Near poor	DNC	DNC
Middle/high income	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

*New data for population groups will be added when available.

The deaths of children after infancy also present a public health concern and an opportunity for prevention. In 1996, 14,074 children aged 1 to 14 years died, representing a death rate of 26.1 per 100,000 children in that age group. The leading cause of death for children of all ages is injury, which accounts for 13.8 deaths per 100,000 preschool children (aged 1 to 4 years) and 8.9 deaths per 100,000 school-aged children (aged 5 to 14 years). Among children aged 1 to 4 years, the leading injury-related causes of death are motor vehicle crashes, drowning, and fires and burns. Among those aged 5 to 14 years, the leading causes of death include motor vehicle crashes and firearms (including unintentional deaths, homicides, and suicides). These deaths are, for the most part, preventable. Other leading causes of death among children that are less likely to be preventable include birth defects (representing 4.1 deaths per 100,000 children aged 1 to 4 years and 1.2 deaths per 100,000 children aged 5 to 14 years), malignant neoplasms (representing 2.7 deaths per 100,000 children aged 1 to 4 years and 2.7 deaths per 100,000 children aged 5 to 14 years), and heart disease (representing 1.4 deaths per 100,000 children aged 1 to 4 years and 0.9 deaths per 100,000 children aged 5 to 14 years).

16-3. Reduce deaths of adolescents and young adults.

Objective	Reduction in Deaths of Adolescents and Young Adults	1998 Baseline*	2010 Target
		Rate per 100,000	
16-3a.	Adolescents aged 10 to 14 years	21.8	16.8
16-3b.	Adolescents aged 15 to 19 years	69.7	43.2
16-3c.	Young adults aged 20 to 24 years	93.8	57.3

*Preliminary data.

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Adolescents and Young Adults, 1997*	16-3a. Deaths of Adolescents Aged 10 to 14 Years	16-3b. Deaths of Adolescents Aged 15 to 19 Years	16-3c. Deaths of Young Adults Aged 20 to 24 Years
	Rate per 100,000		
TOTAL	23.2	74.8	98.6
Race and ethnicity			
American Indian or Alaska Native	24.2	108.9	132.6
Asian or Pacific Islander	16.9	43.3	57.4
Asian	DNC	DNC	DNC
Native Hawaiian and other Pacific Islander	DNC	DNC	DNC
Black or African American	32.1	107.6	175.1
White	21.8	69.5	86.2
Hispanic or Latino	19.0	72.6	101.5
Not Hispanic or Latino	23.7	74.8	97.7
Black or African American	33.3	111.1	181.9
White	21.9	67.7	81.4
Gender			
Female	18.3	43.4	49.5
Male	27.9	104.5	145.3
Family income level			
Poor	DNC	DNC	DNC

Adolescents and Young Adults, 1997*	16-3a. Deaths of Adolescents Aged 10 to 14 Years	16-3b. Deaths of Adolescents Aged 15 to 19 Years	16-3c. Deaths of Young Adults Aged 20 to 24 Years
	Rate per 100,000		
Near poor	DNC	DNC	DNC
Middle/high income	DNC	DNC	DNC
Disability status			
Persons with disabilities	DNC	DNC	DNC
Persons without disabilities	DNC	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

*New data for population groups will be added when available.

The deaths of young adolescents, older adolescents, and young adults are more likely to be due to external causes than to congenital diseases. There were 4,550 deaths among adolescents aged 10 to 14 years in 1996, for a mortality rate of 23.97 per 100,000. The leading cause of death for adolescents in this age group was motor vehicle crashes at 5.8 deaths per 100,000, or 24.2 percent of the total mortality. Other unintentional injuries, (such as falls, drownings, and poisonings) caused 3.91 deaths per 100,000 (16.4 percent); homicides caused 1.76 deaths per 100,000 (7.4 percent); suicides caused 1.56 deaths per 100,000 (6.5 percent); and AIDS caused 0.38 deaths per 100,000 (1.6 percent). Fifty-six percent of the total deaths in this age group, therefore, can be attributed to unnecessary (that is, preventable) causes. Other causes of death for this age group that are less amenable to prevention strategies given current scientific knowledge include malignant neoplasms, which caused 2.66 deaths per 100,000 (11.1 percent); birth defects, which caused 1.13 deaths per 100,000 (4.7 percent); diseases of the heart, which caused 1.08 deaths per 100,000 (4.5 percent); and a combination of other causes, the cause of 4.51 deaths per 100,000 (18.8 percent).¹⁵

There were 14,663 deaths in 1996 among adolescents aged 15 to 19 years, for a death rate of 78.6 per 100,000. The leading cause of death for adolescents in this age group was motor vehicle crashes at 28.55 deaths per 100,000, or 36.3 percent of total deaths. Other unintentional injuries (such as falls, drownings, and poisonings) caused 7.64 deaths per 100,000 (9.7 percent); homicides caused 15.66 deaths per 100,000 (19.9 percent); suicides caused 9.73 deaths per 100,000 (12.4 percent); and AIDS caused 0.26 deaths per 100,000 (0.3 percent). Consequently, a majority (78 percent) of the total mortality in this age group can be attributed to unnecessary (that is, preventable) causes. The remaining 22 percent of deaths among adolescents aged 15 to 19 years resulted mostly from malignant neoplasms which caused 3.67 deaths per 100,000 (4.7 percent); diseases of the heart caused

2.18 deaths per 100,000 (2.8 percent); birth defects caused 1.02 deaths per 100,000 (1.3 percent); and a combination of other causes caused 8.42 deaths per 100,000 (10.7 percent).

Young adults aged 20 to 24 years had a death rate of 101.3 per 100,000 in 1996—a rate 322 percent higher than adolescents aged 10 to 14 years, and 29 percent higher than adolescents aged 15 to 19 years. The leading cause of death for persons aged 20 to 24 years was motor vehicle crashes at 29.88 deaths per 100,000, or 29.5 percent of the total deaths. Other unintentional injuries (such as falls, drownings, and poisonings) caused 10.28 deaths per 100,000 (10.2 percent); homicides caused 20.63 deaths per 100,000 (20.4 percent); suicides caused 14.47 deaths per 100,000 (14.3 percent); and AIDS caused 2.06 deaths per 100,000 (2 percent). Consequently, a majority (76 percent) of the total deaths in this age group can be attributed to unnecessary (that is, preventable) causes. The remaining 24 percent of deaths among young adults aged 20 to 24 years resulted mostly from malignant neoplasms which caused 5.39 deaths per 100,000 (5.3 percent); diseases of the heart caused 3.2 deaths per 100,000 (3.2 percent); birth defects caused 1.08 deaths per 100,000 (1.1 percent); and a combination of other causes caused 12.3 deaths per 100,000 (12.7 percent).

These mortality data, however, do not adequately reflect consequences of sexual behaviors established as individuals in this age group become sexually mature. Illustratively, it is likely that most of the new HIV infections that occur each year occur among those between age 13 and 21 years. Further, about three million new and sexually transmitted disease infections (STDs) in addition to HIV occur among teenagers each year. In addition, about 1 million teenagers become pregnant each year.

Maternal Death and Illness

16-4. Reduce maternal deaths.

Target: 3.3 maternal deaths per 100,000 live births.

Baseline: 8.4 maternal deaths per 100,000 live births in 1997.

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births, 1997	Maternal Deaths Rate per 100,000
TOTAL	8.4
Mother's race and ethnicity	
American Indian or Alaska Native	DSU
Asian or Pacific Islander	DSU
Asian	DSU
Native Hawaiian and other Pacific Islander	DSU
Black or African American	20.8
White	5.8
Hispanic or Latino	8.0
Not Hispanic or Latino	DNA
Black or African American	DNA
White	5.2
Mother's age	
Under 20 years	5.7
20 to 24 years	6.6
25 to 29 years	7.9
30 to 34 years	8.3
35 years and older	16.1
Mother's education level	
Less than high school	DNA
High school graduate	DNA
At least some college	DNA
Mother's disability status	
Mothers with disabilities	DNC
Mothers without disabilities	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

16-5. Reduce maternal illness and complications due to pregnancy.

Target and baseline:

Objective	Reduction in Maternal Illness and Complications	1997 Baseline	2010 Target
		Per 100 Deliveries	
16-5a.	Maternal complications during labor and delivery	32.1	20
16-5b.	Ectopic pregnancies	Developmental	
16-5c.	Postpartum complications, including postpartum depression	Developmental	

Target setting method: Better than the best.

Data source: National Hospital Discharge Survey, CDC, NCHS.

Potential data source: National Ambulatory Medical Care Survey (NAMCS) and National Hospital Discharge Survey (NHDS), CDC, NCHS.

Deliveries, 1997	16-5a. Maternal Complications During Labor and Delivery Rate per 100 Deliveries
TOTAL	32.1
Race and ethnicity	
American Indian or Alaska Native	DSU
Asian or Pacific Islander	DSU
Asian	DNC
Native Hawaiian and other Pacific Islander	DNC
Black or African American	39.2
White	30.7
Hispanic or Latino	DSU
Not Hispanic or Latino	DSU
Black or African American	DSU
White	DSU

Deliveries, 1997	16-5a. Maternal Complications During Labor and Delivery Rate per 100 Deliveries
Age	
Under 15 years	DSU
15 to 19 years	35.8
20 to 24 years	31.5
25 to 29 years	31.1
30 to 34 years	31.4
35 years and older	32.8
Family income level	
Poor	DNC
Near poor	DNC
Middle/high income	DNC

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In 1997, 327 maternal deaths were reported, the major causes of which were hemorrhage, ectopic pregnancy, pregnancy-induced hypertension, embolism, infection, and other complications of pregnancy and childbirth. The overall maternal mortality rate has fluctuated between approximately 7 and 8 per 100,000 live births since 1987 when it was 6.6 per 100,000 live births.³⁶ Moreover, the gap between African Americans and whites remains, with the maternal mortality rate among African Americans 3.5 times that of whites in 1996. The rates among African Americans have been at least three to four times higher than those of whites since 1940. The rate among African Americans also has not declined fluctuating between about 18 and 22 per 100,000 live births.³⁶

Pregnancy and delivery can lead to serious physical and mental health problems for women. In the past, maternal illness and complications were monitored through objectives relating to the ratio of antenatal hospitalizations for pregnancy complications to the total number of deliveries. This ratio has become a less useful measure, however, as rates of antenatal hospitalization in general have declined due to managed care and its emphasis on outpatient treatment. Therefore, attention should be focused on the major causes of maternal illness and complications, particularly those most likely to be associated with maternal death, such as ectopic pregnancy. PID caused by chlamydia and gonorrhea is the leading cause of preventable tubal scarring that can result in ectopic pregnancy. (See Focus Area 25. Sexually Transmitted Diseases.) The outcomes of interest should include not

only prenatal illness and complications and complications during labor and delivery, but also postpartum complications. Postpartum depression, for example, is disabling for a new mother and can compromise her ability to care for her infant.

Prenatal Care

16-6. Increase the proportion of pregnant women who receive early and adequate prenatal care.

Target and baseline:

Objective	Increase in Maternal Prenatal Care	1998 Baseline* (unless noted)	2010 Target
		Percent of Live Births	
16-6a.	Beginning in first trimester of pregnancy	83	90
16-6b.	Early and adequate prenatal care	74 (1997)	90

*Preliminary data.

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births, 1997*	Maternal Prenatal Care	
	16-6a. First Trimester	16-6b. Adequate
	Percent	
TOTAL	83	74
Mother's race and ethnicity		
American Indian or Alaska Native	68	57
Asian or Pacific Islander	82	73
Asian	85	75
Native Hawaiian and other Pacific Islander	74	67
Black or African American	72	66
White	85	76

Live Births, 1997*	Maternal Prenatal Care	
	16-6a. First Trimester	16-6b. Adequate
	Percent	
Hispanic or Latino	74	65
Not Hispanic or Latino	85	76
Black or African American	72	66
White	88	79
Mother's age		
Under 15 years	47	47
15 to 19 years	68	63
20 to 24 years	77	70
25 to 29 years	86	77
30 to 34 years	89	79
35 years and older	88	79
Mother's education level		
Less than high school	68	60
High school graduate	81	73
Some college	91	81
Mother's disability status		
Mothers with disabilities	DNC	DNC
Mothers without disabilities	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

*New data for population groups will be added when available.

Prenatal care includes three major components: risk assessment, treatment for medical conditions or risk reduction, and education. Each component can contribute to reductions in perinatal illness, disability, and death by identifying and mitigating potential risks and helping women to address behavioral factors, such as smoking and alcohol use, that contribute to poor outcomes. Prenatal care is more likely to be effective if women begin receiving care early in pregnancy. Since 1990, the proportion of infants whose mothers entered prenatal care in the first trimester increased 8.8 percent, from 75.8 percent to 82.5 percent. Among African Americans, this proportion grew 19 percent and among Hispanics, 22 percent. Thus, increases in early entry into prenatal care have been concentrated in those populations whose perinatal illness and disability rates and mortality rates are highest and who are most likely to have low incomes. These increases are likely due, in part, to increased access to Medicaid coverage for pregnancy-related services and improved outreach by Medicaid programs.³⁷ In addition, the likelihood of early entry into prenatal care rises with age. The risk of poor birth outcomes is

greatest among the youngest mothers (aged 15 years and under). Clearly, therefore, continued work is needed to educate women, particularly young women, about the need to begin prenatal care early in pregnancy.

Prenatal care should begin early and continue throughout pregnancy, according to accepted standards of periodicity. For example, the American College of Obstetricians and Gynecologists recommends that women receive at least 13 prenatal visits during a full-term pregnancy.³⁸ Therefore, assessment of the adequacy of the care pregnant women receive must include monitoring not only the month of initiation of prenatal care but also the adequacy of the care they receive throughout pregnancy. The Adequacy of Prenatal Care Utilization Index (APNCU) measures two dimensions of care: the adequacy of initiation of care and the adequacy of the use of prenatal services once care has begun (by comparing actual use to the recommended number of visits based on the month of initiation of care and the length of the pregnancy).³⁹ These dimensions are combined to classify each woman's prenatal care history as inadequate, intermediate, adequate, or adequate-plus. The baseline rates presented above include all women who received either adequate or adequate-plus care.

Overall, nearly three-quarters of women receive adequate prenatal care. However, this proportion varies across racial and ethnic groups. Certain groups, such as American Indians or Alaska Natives and Samoans, are particularly likely to receive less-than-adequate prenatal care. The likelihood of receipt of adequate prenatal care rises with maternal age, with fewer than half of pregnant women aged 15 years and under receiving adequate care. Prevention of unwanted pregnancy in adolescents and education of women about the need for early, continuous prenatal care are essential.

16-7. (Developmental) Increase the proportion of pregnant women who attend a series of prepared childbirth classes.

Potential data sources: National Pregnancy and Health Survey, NIH, NICHD; National Survey of Family Growth (NSFG) or National Health Interview Survey (NHIS), CDC, NCHS.

As part of comprehensive prenatal care, a formal series of prepared childbirth classes conducted by a certified childbirth educator is recommended for all women by the Expert Panel on the Content of Prenatal Care.⁴⁰ These classes can help reduce women's pain⁴¹ and anxiety⁴² as they approach childbirth, making delivery a more pleasant experience and preparing women for what they will face as they give birth. A full series of sessions is recommended for women who have never attended. A refresher series of one or two classes is recommended for women who attended during a previous pregnancy. At a minimum, the childbirth classes should include information regarding the physiology of labor and birth, exercises and self-help techniques for labor, the role of support persons, family roles and adjustments, and preferences for care during labor and birth. The classes

also should include an opportunity for the mother and her partner to have questions answered about providers, prenatal care, and other relevant issues, as well as to receive information regarding birth settings and cesarean childbirth. Attendance is recommended during the third trimester of pregnancy so that information learned will be used relatively soon after presentation. Classes should begin at the 31st or 32nd week and be completed no later than 38 weeks. The refresher class should be completed at any time between 36 and 38 weeks.

Obstetrical Care

16-8. Increase the proportion of very low birth weight (VLBW) infants born at Level III hospitals or subspecialty perinatal centers.

Target: 90 percent.

Baseline: 73 percent of VLBW infants were born at Level III hospitals or subspecialty perinatal centers in 1996-97.

Target setting method: 25 percent improvement (better than the best will be used when data are available.)

Data source: Title V Reporting System, HRSA, MCHB.

Much research has demonstrated the benefits of delivering high-risk infants in settings that have the technological capacity to care for them. Specifically, research has shown that VLBW infants have lower death rates when they are delivered at Level III hospitals, which are equipped to care for very small infants.^{43, 44, 45} To ensure that high-risk pregnant women have access to appropriate levels of obstetric care, many States have implemented perinatal regionalization strategies and protocols for the transfer of high-risk women to Level III facilities. Evidence, however, indicates that these systems may be eroding as health care networks and financing systems change.^{43, 46} The proportion of VLBW infants who are delivered in the Level III obstetric hospitals best equipped to provide appropriate neonatal care should be measured to monitor the continuing effectiveness of these systems and the appropriateness of the level of care delivered to high-risk pregnant women and infants.

16-9. Reduce cesarean deliveries among low-risk (full term, singleton, vertex presentation) women.

Target and baseline:

Objective	Reduction in Cesarean Delivery	1997 Baseline	2010 Target
		Percent	
16-9a.	No prior cesarean delivery	17.8	15.5
16-9b.	Prior cesarean delivery	71	63

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Low-Risk Women Who Gave Birth, 1997	16-9a. No Prior Cesarean Delivery	16-9b. Prior Cesarean Delivery
	Percent	
TOTAL	17.8	71
Mother's race and ethnicity		
American Indian or Alaska Native	16.3	64
Asian or Pacific Islander	17.7	68
Asian	18.8	70
Native Hawaiian and other Pacific Islander	15.6	66
Black or African American	20.0	72
White	17.4	71
Hispanic or Latino	17.4	75
Not Hispanic or Latino	17.9	70
Black or African American	20.1	72
White	17.4	69
Mother's age		
Under 15 years old	12.0	DSU
15 to 19 years	12.0	66
20 to 24 years	16.2	69
25 to 29 years	19.3	70
30 to 34 years	23.7	71
35 years and older	31.5	74

Low-Risk Women Who Gave Birth, 1997	16-9a.	16-9b.
	No Prior Cesarean Delivery	Prior Cesarean Delivery
	Percent	
Mother's education level		
Less than high school	14.0	71
High school graduate	18.2	72
At least some college	19.5	70
Mother's disability status		
Mothers with disabilities	DNC	DNC
Mothers without disabilities	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

During the 1980s, rates of cesarean deliveries rose steadily, with a peak rate of 24.7 percent of deliveries reported in 1988. Since then, the rate has been slowly decreasing, with the majority of the decline attributable to a reduction in the rates of primary cesarean deliveries. In 1989, the rate of vaginal births among women who had a previous cesarean delivery was 18.9 percent; in 1996 it increased to 28.3 percent.⁴⁷ The improvements are likely to be attributable to use of such strategies as clearer guidelines for trials of labor and labor management, continual labor support, and focused attention on physician practice patterns.⁴⁸ Expert opinion called for use of risk-adjusted rates of cesarean deliveries (that is, rates standardized by patient characteristics) to monitor progress over time.⁴⁹ (The targets presented here apply to the population as a whole and are not intended to be used as practice outcome objectives for individual physicians or institutions, as the medical needs of the patients in each practice will vary.) In addition to monitoring rates of cesarean deliveries, the outcomes of these deliveries (for both the mother and the infant) should be watched closely to assure that changes in the mode of delivery do not put women or their infants at risk.

Risk Factors

16-10. Reduce low birth weight (LBW) and very low birth weight (VLBW).

Target and baseline:

Objective	Reduction in Low and Very Low Birth Weight	1998 Baseline*	2010 Target
		Percent	
16-10a.	Low birth weight (LBW)	7.6	5.0
16-10b.	Very low birth weight (VLBW)	1.4	0.9

*Preliminary data.

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births, 1997*	16-10a. Low Birth Weight	16-10b. Very Low Birth Weight
	Percent	
TOTAL	7.5	1.4
Mother's race and ethnicity		
American Indian or Alaska Native	6.8	1.2
Asian or Pacific Islander	7.2	1.1
Asian	7.1	1.0
Native Hawaiian and other Pacific Islander	DSU	DSU
Black or African American	13.0	3.0
White	6.5	1.1
Hispanic or Latino	6.4	1.1
Not Hispanic or Latino	7.8	1.5
Black or African American	13.1	3.1
White	6.5	1.1
Gender		
Female	8.1	1.4
Male	7.0	1.4

Live Births, 1997*	16-10a. Low Birth Weight	16-10b. Very Low Birth Weight
	Percent	
Mother's age		
Under 15 years	13.6	3.1
15 to 19 years	9.5	1.8
20 to 24 years	7.4	1.4
25 to 29 years	6.6	1.2
30 to 34 years	6.9	1.3
35 years and older	8.6	1.7
Mother's education level		
Less than high school	9.0	1.6
High school graduate	7.9	1.5
At least some college	6.4	1.2
Mother's disability status		
Mothers with disabilities	DNC	DNC
Mothers without disabilities	DNC	DNC

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*New data for population groups will be added when available.

LBW is the risk factor most closely associated with neonatal death; thus, improvements in infant birth weight can contribute substantially to reductions in the infant death rate. Of all infants born at low birth weight, the smallest (those weighing less than 1,500g) are at highest risk of dying in their first year. However, some researchers have proposed that further improvement in the survival of VLBW infants is nearly impossible, and reduction in the underlying rate of VLBW births is the only avenue toward reduction of neonatal death rates.⁵⁰ Another important issue is the long-term effects of LBW on affected infants who survive their first year, as these infants are more likely to experience long-term developmental and neurologic disabilities than are infants of normal birth weight.^{51, 52} Recent increases in LBW are due largely to preterm delivery related to increases in multiple gestation.

Smoking accounts for 20 to 30 percent of all LBW births in the United States. The effect of smoking on LBW rates appears to be attributable to intrauterine growth retardation rather than to preterm delivery.⁶ VLBW is primarily associated with preterm birth, which may be associated with the use of illicit drugs during pregnancy.

16-11. Reduce preterm births.

Target and baseline:

Objective	Reduction in Preterm Births	1997 Baseline	2010 Target
		Percent	
16-11a.	Total preterm	11.4	7.6
16-11b.	Live births at 32 to 36 weeks of gestation	9.4	6.4
16-11c.	Live births at less than 32 weeks of gestation	1.9	1.1

Target setting method: Better than the best.

Data source: National Vital Statistics System (NVSS), CDC, NCHS.

Live Births, 1997	16-11a. All Preterm Births	16-11b. 32 to 36 Weeks of Gestation	16-11c. Less Than 32 Weeks of Gestation
	Percent		
TOTAL	11.4	9.4	1.9
Mother's race and ethnicity			
American Indian or Alaska Native	12.2	10.2	2.1
Asian or Pacific Islander	10.2	8.8	1.4
Asian	9.5	8.3	1.2
Native Hawaiian and other Pacific Islander	11.0	9.1	1.9
Black or African American	17.5	13.3	4.2
White	10.2	8.7	1.5
Hispanic or Latino	11.2	9.5	1.7
Not Hispanic or Latino	11.4	9.4	2.0
Black or African American	17.6	13.4	4.2
White	9.9	8.5	1.5
Gender			
Female	DNA	DNA	DNA
Male	DNA	DNA	DNA

Live Births, 1997	16-11a. All Preterm Births	16-11b. 32 to 36 Weeks of Gestation	16-11c. Less Than 32 Weeks of Gestation
	Percent		
Mother's age			
Under 15 years	21.8	16.0	5.8
15 to 19 years	13.7	11.0	2.7
20 to 24 years	11.2	9.3	1.9
25 to 29 years	10.3	8.7	1.6
30 to 34 years	10.6	8.9	1.7
35 years and older	12.6	10.5	2.1
Mother's education level			
Less than high school	13.4	11.0	2.4
High school graduate	11.8	9.7	2.1
At least some college	9.9	8.4	1.5
Mother's disability status			
Mothers with disabilities	DNC	DNC	DNC
Mothers without disabilities	DNC	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

Approximately two-thirds of LBW infants and 98 percent of VLBW infants are born preterm. In addition, preterm birth is the leading cause of those neonatal deaths not associated with birth defects. Survival rates of infants have been shown to increase as gestational age advances, even among very preterm infants.^{53, 54} Therefore, reduction in preterm delivery holds the greatest promise for overall reduction in infant illness, disability, and death. Because the specific causes of preterm delivery are unclear, research is needed before tailored interventions can be developed.^{55, 56} Preterm birth is associated with a number of modifiable risk factors, including the use of alcohol, tobacco, or other drugs during pregnancy^{57, 58} and low prepregnancy weight or low weight gain during pregnancy.^{59, 60} Other important risk factors for preterm birth are vaginal infections^{61, 62, 63} and domestic violence.

Rates of preterm delivery in the United States increased over the last three decades of the 20th century.^{4, 59} Between 1989 and 1996, this increase was due largely to an increase in multiple gestation. The gap between African American and white infants persists as well, for reasons that are largely unexplained⁶⁴ and have been shown to be independent of other known risk factors.^{57, 65} Risk factors that African American women may disproportionately experience include short interpregnancy intervals⁶⁶ and exposure to psychosocial stress.^{65, 67}

16-12. (Developmental) Increase the proportion of mothers who achieve a recommended weight gain during their pregnancies.

Potential data source: National Vital Statistics System (NVSS), CDC, NCHS.

Current evidence indicates that gestational weight gain, particularly during the second and third trimesters, is an important determinant of fetal growth. Inadequate weight gain during pregnancy is associated with an increased risk of IUGR, LBW, and infant death.^{68, 69, 70} Maternal weight gain is susceptible to intervention and represents an avenue for prevention of poor birth outcomes. The Institute of Medicine's 1990 guidelines for weight gain in pregnancy recommend a graduated level of weight gain based on a woman's prepregnancy body mass index (BMI) (that is, the ratio of her weight to her height).⁶⁸ Under these guidelines, a woman with normal BMI should gain 25 to 35 pounds during pregnancy. Those with below-normal BMI should gain 28 to 40 pounds. Overweight women should gain 15 to 25 pounds.

In 1988, approximately three-quarters of married women who delivered at full term gained the recommended weight during pregnancy.⁷¹ Two groups of women who continue to gain less than the recommended level of weight during pregnancy—teenagers and African American women—also are at particularly high risk for having LBW infants and other adverse pregnancy outcomes.

16-13. Increase the percentage of healthy full-term infants who are put down to sleep on their backs.

Target: 70 percent.

Baseline: 35 percent of healthy full-term infants were put down to sleep on their backs in 1996.

Target setting method: Better than the best.

Data source: National Infant Sleep Position Study, NIH, NICHD.

Infants, 1996	Put Down To Sleep on Back Percent
TOTAL	35
Mother's race and ethnicity	
American Indian or Alaska Native	DNA
Asian or Pacific Islander	DNA

Infants, 1996	Put Down To Sleep on Back Percent
Asian	DNC
Native Hawaiian and other Pacific Islander	DNC
Black or African American	17
White	37
Hispanic or Latino	28
Not Hispanic or Latino	DNA
Black or African American	DNA
White	DNA
Gender	
Female	DNA
Male	DNA
Mother's age	
Under 15 years	DNA
15 to 19 years	DNA
20 to 24 years	DNA
25 to 29 years	DNA
30 to 34 years	DNA
35 years and older	DNA
Mother's education level	
Less than high school	DNC
High school graduate	DNC
At least some college	DNC
Mother's disability status	
Mothers with disabilities	DNC
Mothers without disabilities	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

Much research has shown that a nonprone sleeping position (that is, sleeping on the side or back rather than the stomach) greatly decreases the risk of SIDS among healthy full-term infants.^{72, 73} However, healthy preterm infants have been shown to be more vulnerable to respiratory problems when put to sleep on their backs.⁷⁴ The American Academy of Pediatrics has recommended that healthy full-term infants be put down to sleep on their backs. The National Institute of Child Health and Human Development and the Maternal and Child Health Bureau instituted the "Back to Sleep" campaign in 1994 to educate parents and physicians about this

recommendation. While the percentage of infants put to sleep on their stomachs dropped dramatically between 1992 and 1997, much of the improvement was in the percentage of infants put to sleep on their sides. Although not as dangerous as the stomach, from this position infants may roll onto their stomachs. Therefore, the objective focuses on increasing the percentage of infants who are put down to sleep on their backs.

Developmental Disabilities and Neural Tube Defects

16-14. Reduce the occurrence of developmental disabilities.

Target and baseline:

Objective	Reduction in Developmental Disabilities in Children	1991–94 Baseline	2010 Target
		Rate per 10,000	
16-14a.	Mental retardation	131*	124
16-14b.	Cerebral palsy	32.2†	31.5
16-14c.	Autism spectrum disorder	Developmental	
16-14d.	Epilepsy	Developmental	

*Children aged 8 years in metropolitan Atlanta, GA, having an IQ of 70 or less.

†Children aged 8 years in metropolitan Atlanta, GA.

Target setting method: 5 percent improvement.

Data source: Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), CDC, NCEH.

Children Aged 8 Years, Atlanta, GA, 1991–94	16-14a. Mental Retardation	16-14b. Cerebral Palsy
	Rate per 10,000	
TOTAL	131	32.2
Race and ethnicity		
American Indian or Alaska Native	DNA	DNA
Asian or Pacific Islander	DNA	DNA
Asian	DNC	DNC
Native Hawaiian and other Pacific Islander	DNC	DNC
Black or African American	210	38.4
White	85	30.4

Children Aged 8 Years, Atlanta, GA, 1991–94	16-14a. Mental Retardation	16-14b. Cerebral Palsy
	Rate per 10,000	
Hispanic or Latino	DNA	DNA
Not Hispanic or Latino	DNA	DNA
Black or African American	DNA	DNA
White	DNA	DNA
Gender		
Female	107	30.8
Male	154	35.5
Family income level		
Poor	DNC	DNC
Near poor	DNC	DNC
Middle/high income	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

Specific developmental disabilities will be monitored among school-aged children since not all occurrences are manifested or recognized until those ages. A reduction in the rate of LBW, as proposed in objective 16-10, can be expected to result in a lower number of occurrences of most developmental disabilities, because LBW is such a strong risk factor. Interventions to reduce the occurrence of some intrauterine infections (for example, congenital rubella syndrome) and increased access to genetic counseling should reduce prenatal causes of developmental disabilities. The early identification and prophylactic treatment of sickle-cell disease are expected to reduce the occurrence of postnatal cerebrovascular complications, which are known postnatal causes of cerebral palsy and mental retardation. Increased safety belt use and other measures to prevent unintentional childhood injury, interventions to prevent child abuse, *Haemophilus influenzae* immunization, and increased access to medical care to reduce meningitis also will reduce the occurrences of developmental disabilities due to postnatal causes.

The Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) is the only high-quality surveillance system that monitors the prevalence of mental retardation and other developmental disabilities. MADDSP is a regional data source from a principally urban area, and therefore MADDSP findings cannot be generalized to the Nation; in particular, MADDSP findings may not be representative of rural regions. Efforts are underway to use MADDSP methods to build similar data systems in other regions of the country.

16-15. Reduce the occurrence of spina bifida and other neural tube defects (NTDs).

Target: 3 new cases per 10,000 live births.

Baseline: 6 new cases of spina bifida or another NTD per 10,000 live births in 1996.

Target setting method: 50 percent improvement (better than the best will be used when data are available).

Data source: National Birth Defects Prevention Network (NBDPN), CDC, NCEH.

Live Births, 1996	New Cases of Spina Bifida or Other NTDs Rate per 10,000
TOTAL	6
Mother's race and ethnicity	
American Indian or Alaska Native	DNA
Asian or Pacific Islander	DNA
Asian	DNC
Native Hawaiian and other Pacific Islander	DNC
Black or African American	DNA
White	DNA
Hispanic or Latino	DNC
Not Hispanic or Latino	DNC
Black or African American	DNC
White	DNC
Gender	
Female	DNA
Male	DNA
Mother's education level	
Less than high school	DNC
High school graduate	DNC
At least some college	DNC
College graduate	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

16-16. Increase the proportion of pregnancies begun with an optimum folic acid level.

Target and baseline:

Objective	Increase in Pregnancies Begun With Optimum Folic Acid Level	1991–94 Baseline*	2010 Target
		Percent	
16-16a.	Consumption of at least 400 µg of folic acid each day from fortified foods or dietary supplements by nonpregnant women aged 15 to 44 years	21	80
		Number	
16-16b.	Median RBC folate level among nonpregnant women aged 15 to 44 years	161 ng/ml	220 ng/ml

*Preliminary estimate.

Target setting method: Better than the best.

Data source: National Health and Nutrition Examination Survey (NHANES), CDC, NCHS.

Nonpregnant Women Aged 15 to 44 Years, 1991–94	16-16a. Adequate Folic Acid Percent	16-16b. Median RBC Folate Level ng/ml
TOTAL	21	161
Race and ethnicity		
American Indian or Alaska Native	DSU	DSU
Asian or Pacific Islander	DSU	DSU
Asian	DNC	DNC
Native Hawaiian and other Pacific Islander	DNC	DNC
Black or African American	DNA	DNA
White	DNA	DNA
Hispanic or Latino	DSU	DSU
Mexican American	13	144
Not Hispanic or Latino	DSU	DNA
Black or African American	17	123
White	23	170

Nonpregnant Women Aged 15 to 44 Years, 1991–94	16-16a. Adequate Folic Acid Percent	16-16b. Median RBC Folate Level ng/ml
Education level		
Less than high school	DNC	DNA
High school graduate	DNC	DNA
At least some college	DNC	DNA
Disability status		
Persons with disabilities	DSU	DNA
Persons without disabilities	DSU	DNA

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

Note: Data are preliminary.

NTDs, including spina bifida, occur when the fetal neural tube fails to close fully, interrupting development of the central nervous system. Approximately 50 percent of pregnancies affected with NTDs may be prevented with adequate consumption of folic acid from 1 month before conception through the first 3 months of pregnancy.⁷⁵ In 1992, the U.S. Public Health Service (PHS) recommended that all women of childbearing age consume 400 micrograms of folic acid daily. For women who already have had an NTD-affected pregnancy, PHS recommends that women consult with a health care professional about taking a much larger amount of folic acid—4,000 micrograms (4.0 milligrams)—when planning a pregnancy.⁷⁶ In 1998, the Institute of Medicine further recommended that to reduce the risk of an NTD-affected pregnancy, all women capable of becoming pregnant should consume 400 micrograms of folic acid daily, from fortified foods or supplements or a combination of the two, in addition to consuming folate-rich foods, such as orange juice, green vegetables, and beans.⁷⁷

Most grain products (including enriched flour, breads, breakfast cereals, rice, and pasta) now are fortified with folic acid. However, the amount of folic acid that some segments of the reproductive-aged population might receive through their diet may not adequately meet the PHS recommendation of 400 micrograms daily. Thus, women capable of becoming pregnant need to review their dietary options, eat a diet that includes folate-rich foods, and target consumption of folic acid-fortified foods, as well as take a folic acid-containing supplement.

Prenatal Substance Exposure

16-17. Increase abstinence from alcohol, cigarettes, and illicit drugs among pregnant women.

Objective	Increase in Reported Abstinence in Past Month From Substances by Pregnant Women*	1996–97 Baseline Percent	2010 Target
16-17a.	Alcohol	86	94
16-17b.	Binge drinking	99	100
16-17c.	Cigarette smoking†	87	98
16-17d.	Illicit drugs	98	100

*Pregnant women aged 15 to 44 years.

†Smoking during pregnancy for all women giving birth in 1997 in 46 States, the District of Columbia, and New York City.

Target setting method: Better than the best for 16-17a, and 16-17c; complete elimination for 16-17b and 16-17d.

Data sources: National Household Survey on Drug Abuse, SAMHSA for 16-17a, 16-17b, and 16-17-d. National Vital Statistics System, CDC, NCHS for 16-17c.

Pregnant Women Aged 15 to 44 Years, 1996–97 (unless noted)	16-17a. Alcohol Abstinence, Past Month	16-17b. No Binge Drinking, Past Month	16-17c. No Cigarette Smoking, 1997*	16-17d. No Drugs, Past Month
Percent				
TOTAL	86	99	87	98
Race and ethnicity				
American Indian or Alaska Native	DNA	DNA	79	DNA
Asian or Pacific Islander	DNA	DNA	97	DNA
Asian	DNC	DNC	98	DNC
Native Hawaiian and other Pacific Islander	DNC	DNC	85	DNC
Black or African American	DNA	DNA	90	DNA
White	DNA	DNA	86	DNA
Hispanic or Latino	93	99	96	99
Not Hispanic or Latino	DNA	DNA	85	DNA
Black or African American	83	99	90	95
White	85	99	83	98

Pregnant Women Aged 15 to 44 Years, 1996–97 (unless noted)	16-17a. Alcohol Abstinence, Past Month	16-17b. No Binge Drinking, Past Month	16-17c. No Cigarette Smoking, 1997*	16-17d. No Drugs, Past Month
	Percent			
	Education level (aged 18 to 44 years)			
Less than high school	79	99	77	92
High school graduate	91	99	83	100
At least some college	DNA	98	94	DNA
College graduate	DNA	DNA	98	DNA
Disability status				
Persons with disabilities	DNC	DNC	DNC	DNC
Persons without disabilities	DNC	DNC	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

*Smoking during pregnancy for all women giving birth in 1997 in 46 States, the District of Columbia, and New York City.

A range of effects, including spontaneous abortion, LBW, and preterm delivery, have been associated with prenatal use of licit and illicit drugs, including alcohol, tobacco, cocaine, and marijuana. As discussed above, tobacco is associated with LBW and spontaneous abortion.⁷⁸ Heavy alcohol use is associated with FAS,⁷⁹ and even moderate alcohol use has demonstrated effects on preterm delivery.⁸⁰ The use of cocaine during pregnancy is associated with premature birth and impaired fetal growth.^{8, 81, 82, 83} In addition, women who use cocaine are at especially high risk of infectious diseases, including hepatitis B and HIV. Exposure to marijuana in utero may be associated with LBW, preterm birth, and neurobehavioral functioning. However, isolating the effects of marijuana use on newborns is difficult because users of the drug often use alcohol and tobacco as well.⁷⁸

Self-reported use of illicit drugs, such as cocaine and marijuana, is quite rare, with 97.5 percent of pregnant women reporting abstaining from these drugs. Rates of abstinence from harmful substances during pregnancy appear to be declining slowly. The use of alcohol during pregnancy, despite the established health risk, exemplifies this trend. In 1996-97, 86 percent of pregnant women abstained from alcohol use, an increase of 9 percent from the 1988 baseline. Rates of frequent drinking (at least seven drinks per week or at least five drinks on any occasion in the past month) among pregnant women have begun to decline, with only 1.3 percent of pregnant women reporting recent binge drinking in 1996-97, compared to 2.9 percent in 1994-95. Unintentional alcohol exposure is particularly likely to occur early in pregnancy, before a woman knows she is pregnant. In addition to the objectives presented here, objectives in Focus Area 26. Substance Abuse, address alcohol consumption among women of reproductive age and tobacco use by pregnant women.

16-18. (Developmental) Reduce the occurrence of fetal alcohol syndrome (FAS).

Potential data source: Fetal Alcohol Syndrome Network (FASNet), CDC, NCEH.

FAS is one of the leading preventable causes of mental retardation and a leading cause of birth defects, including growth deficiency and microcephaly. Affected children also are likely to show infantile irritability, poor coordination, hypotonia, and attention deficit/hyperactivity disorder.^{80, 84} The diagnosis of FAS is based on three criteria: prenatal or postnatal growth retardation or both, central nervous system impairment, and characteristic facial malformations. Abnormalities of other organs and systems, however, have been noted in combination with these characteristics.⁸⁵ Estimates of the cases of FAS vary from 0.2 to 1.0 per 1,000 live births. In addition to FAS, studies have documented more subtle growth and neurodevelopmental deficits among children whose mothers drank alcohol during pregnancy. Alcohol-related birth defects and alcohol-related neurodevelopmental disorders are thought to occur three to four times more often than diagnosed cases of FAS. Because of these lifelong effects, and because a safe level of alcohol consumption during pregnancy has not been identified, the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists recommend that women who are pregnant or are planning a pregnancy abstain from the use of alcohol.^{86, 87}

Despite broad agreement on the importance of FAS, consistent diagnosis of the syndrome at birth has been difficult to achieve. Thus, accurately estimating the number or proportion of infants affected by FAS is challenging for a number of reasons: the difficulty of evaluating an infant's central nervous system, lack of training among clinicians, inconsistent diagnostic criteria, clinicians' tendency to avoid associating their patients with the stigma of alcohol problems, and failures of mothers to report alcohol intake during gestation.⁷

Breastfeeding, Newborn Screening, and Service Systems

16-19. Increase the proportion of mothers who breastfeed their babies.

Target and baseline:

Objective	Increase in Mothers Who Breastfeed	1998 Baseline	2010 Target
		Percent	
16-19a.	In early postpartum period	64	75
16-19b.	At 6 months	29	50
16-19c.	At 1 year	16	25

Target setting method: Better than the best.

Data source: Mothers' Survey, Abbott Laboratories, Inc., Ross Products Division.

Mothers, 1998	Breastfed		
	16-19a. Early Postpartum	16-19b. 6 Months	16-19c. 1 Year
	Percent		
TOTAL	64	29	16
Race and ethnicity			
American Indian or Alaska Native	DNC	DNC	DNC
Asian or Pacific Islander	DNC	DNC	DNC
Asian	DNC	DNC	DNC
Native Hawaiian and other Pa- cific Islander	DNC	DNC	DNC
Black or African American	45	19	9
White	68	31	17
Hispanic or Latino	66	28	19
Not Hispanic or Latino	DNC	DNC	DNC
Black or African American	DNC	DNC	DNC
White	DNC	DNC	DNC
Education level			
Less than high school	48	23	17
High school graduate	55	21	12
Some college	55	21	12
College graduate	78	40	22
Disability status			
Persons with disabilities	DNC	DNC	DNC
Persons without disabilities	DNC	DNC	DNC

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

Breast milk is widely acknowledged to be the most complete form of nutrition for infants, with a range of benefits for infants' health, growth, immunity, and development. The benefits of breastfeeding include decreased new cases or severity of diarrhea,^{19, 20, 21, 22, 30} respiratory infections,^{23, 24} and ear infections,^{20, 25, 26} among others, and reduced cost to the family.^{27, 28} In addition, breastfeeding has been shown to improve maternal health, with demonstrated effects, including reduction in post-

partum bleeding,²⁹ earlier return to prepregnancy weight,³⁰ reduced risk of premenopausal breast cancer,³¹ and reduced risk of osteoporosis,³² continuing long after the postpartum period. In general, the American Academy of Pediatrics considers breastfeeding to be “the ideal method of feeding and nurturing infants.”¹⁰

Universal breastfeeding is not recommended in the United States. Women who use illicit drugs, who have active, untreated tuberculosis, or who test positive for HIV, as well as those who use certain prescribed drugs, should not breastfeed.^{11, 88} In general, however, increasing the rate of breastfeeding, particularly among the low-income, racial, and ethnic populations less likely to begin breastfeeding in the hospital or to sustain it throughout the infant’s first year, is an important public health goal.

Rates of breastfeeding are highest among college-educated women, and those aged 35 years and older. The lowest rates of breastfeeding are found among those whose infants are at highest risk of poor health and development: those aged 21 years and younger and those with low educational levels. However, many of these groups have shown the greatest increase in breastfeeding rates since 1989. Rates of breastfeeding among African American women during the postpartum period increased 65 percent, and rates of African American women breastfeeding at 6 months grew 81 percent between 1988 and 1997. Breastfeeding rates among women aged 20 years and under at both periods also increased substantially, as did those among women with a grade-school education.¹² While these improvements are encouraging, education of new mothers and their partners; education of health providers; changes in routine maternity ward practices; social support, including support from employers; and greater media portrayal of breastfeeding as the normal method of infant feeding are needed to increase breastfeeding rates among those at highest risk.

16-20. (Developmental) Ensure appropriate newborn bloodspot screening, followup testing, and referral to services.

16-20a. Ensure that all newborns are screened at birth for conditions mandated by their State-sponsored newborn screening programs, for example, phenylketonuria and hemoglobinopathies.

16-20b. Ensure that followup diagnostic testing for screening positives is performed within an appropriate time period.

16-20c. Ensure that infants with diagnosed disorders are enrolled in appropriate service interventions within an appropriate time period.

Potential data source: Title V Performance Measures, HRSA, MCHB, National Newborn Screening and Genetic Resource Center.

Newborn screening (NBS) programs began in the early 1960s with the development of a screening test for phenylketonuria and a system for blood sample collection on filter paper and transportation of that sample. Since then, all States and

some territories of the United States have included NBS as part of their preventive public health system. NBS programs in the United States were the first population-based screening programs for genetic conditions and signaled the integration of genetic testing into public health programs. The mass screening of four million infants per year in the United States has been heralded as a successful program that is cost-effective and reduces illness, disability, and death associated with inherited conditions. The universal acceptance of newborn screening for specified conditions since 1960 attests to the undeniable benefits that flow from testing and appropriate treatment and intervention.

The array of screening tests performed by each State varies and is changing constantly. All State programs now include screening for phenylketonuria and congenital hypothyroidism. More than 40 programs screen for sickle cell disease and almost all screen for galactosemia. Others include congenital adrenal hyperplasia, homocystinuria, maple syrup urine disease, biotinidase deficiency, and tyrosinemia. A few States also include cystic fibrosis, additional metabolic disorders, and some other conditions such as congenital infections. Virtually all States treat or refer for treatment those with a confirmed diagnosis. However, some disorders are more uniformly screened for than others, and followup testing and early initiation of preventive treatment is uneven. For example, screening for PKU and congenital hypothyroidism is virtually universal, although reporting is not.^{89, 90} Screening and followup for galactosemia, sickle cell disease, and other hemoglobinopathies have been less consistent.^{89, 90} Sickle cell disease can lead to severe illness and early death and galactosemia leads to an increased risk of death from overwhelming infection in early infancy, failure to thrive, vomiting, liver disease, and mental retardation in untreated survivors.⁹¹ Therefore, it is vital that screening be universally available, that screening be of the highest quality, that diagnostic testing be provided for those newborns who screen positive, and that followup treatment be offered to children with diagnosed disorders.^{92, 93, 94}

16-21. (Developmental) Reduce hospitalization for life-threatening sepsis among children aged 4 years and younger with sickling hemoglobinopathies.

Potential data source: National Hospital Discharge Survey (NHDS), CDC, NCHS.

Significant illness, disability, and death are associated with sickle cell disease because of increased susceptibility to severe bacterial infections—meningitis, pneumonia, and septicemia—all major causes of death among children with the disorder.^{95, 96, 97} Life-threatening episodes of sepsis from pneumococcus and other organisms are well recognized complications of sickle cell disease in children. The efficacy of daily oral penicillin prophylaxis in preventing infection among young children with sickle cell disease has been demonstrated.⁹⁵ Sepsis rates have been shown to be clearly improved by prophylactic therapy in the U.S. penicillin trial, but concerns about actual use of penicillin in large populations and about

penicillin-resistant organisms necessitate continued monitoring of sepsis rates in large populations.

16-22. (Developmental) Increase the proportion of children with special health care needs who have access to a medical home.

Potential data source: Title V Reporting System.

Historically, services for children with special health care needs have been difficult for families to access and for providers to coordinate. Families must navigate a variety of organizations and providers and often face geographic and financial barriers to care. Primary care providers in the community are not always comfortable providing care to children with complex needs, nor do they have time to coordinate the variety of resources families need. A lack of knowledge of comprehensive needs and corresponding community-based resources and payment mechanisms presents a challenge for both families and providers. Poor communication between families and providers and cross-cultural misunderstandings are additional concerns for both families and providers.

Care for children with special health care needs should be provided and coordinated through a “medical home” that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent and linguistically appropriate. Physicians and parents share responsibility for ensuring that children and their families have access to all the medical and nonmedical services needed to help them achieve their maximum potential. The attributes of such a medical home are defined below:

- Accessible care is care is provided in the child’s community, in which all insurance, including Medicaid, is accepted and changes in insurance status are accommodated.
- Family-centered care recognizes that the family is the principal caregiver and the center of strength and support for children. Family-centered services share unbiased and complete information with families on an ongoing basis.
- Continuous care assures that the same primary pediatric health care professionals are available from infancy through adolescence and provide assistance with transitions (to school, home, and adult services).
- Comprehensive health care is available 24 hours a day, 7 days a week, and addresses preventive, primary, and tertiary needs.
- Coordinated care links families to support, educational, and community-based services, and information is centralized.

- Compassionate caregivers express concern for the well-being of the child and family.
- Culturally competent and linguistically appropriate care recognizes, values, and respects the family's cultural background.^{98, 99, 100, 101, 102}

16-23. Increase the proportion of Territories and States that have service systems for children with special health care needs.

Target: 100 percent.

Baseline: 15.7 percent of Territories and States met Title V for service systems for Children with Special Health Care Needs in FY 1997.

Target setting method: Total coverage.

Data source: Title V reporting system.

Children with special health care needs and their families often require a range of services.¹⁰³ Health services, for example, include health education and health promotion; preventive and primary care, including routine screening for impairments of vision, hearing, speech, and language and assessment of physical and psychosocial milestones; specialized diagnostic and therapeutic services; and habilitation and rehabilitation services. Early intervention services are necessary as well, as are educational, vocational, and mental health services and support services for children and their families. Enabling services, such as transportation and child care, are necessary to ensure access to care. Transition services are needed to assist in the progression from adolescent health care to adult services and from school to work.

Families continuously face the challenge of obtaining and coordinating the primary and special services their children require. Differing eligibility criteria, duplication and gaps in services, inflexible funding sources, and poor coordination among service sectors are some of the barriers consistently reported. Many of these issues can be resolved only through the concerted effort of a system of services—the broad array of public and private entities serving children and families in the Nation's communities. These service systems should ensure access to a source of insurance for primary and specialty care and enabling services, an identified medical home, and care coordination. Families and their care professionals should participate in the design and implementation of these service systems.¹⁰⁴ This collaborative partnership will strengthen the ability of families to care for their children with special needs and will enable children with complex conditions to live at home with their families.

Related Objectives From Other Focus Areas

1. Access to Quality Health Services

- 1-1. Persons with health insurance
- 1-2. Health insurance coverage for clinical preventive services
- 1-4. Source of ongoing care
- 1-5. Usual primary care provider
- 1-6. Difficulties or delays in obtaining needed health care
- 1-9. Hospitalization for ambulatory-care-sensitive conditions
- 1-12. Single toll-free number for poison control centers
- 1-13. Trauma care systems
- 1-15. Special needs of children

5. Diabetes

- 5-8. Gestational diabetes

6. Disability and Secondary Conditions

- 6-2. Feelings and depression among children with disabilities
- 6-7. Congregate care of children and adults with disabilities
- 6-9. Children and youth with disabilities included in regular education programs

7. Educational and Community-Based Programs

- 7-1. High school completion
- 7-2. School health education
- 7-4. School nurse-to-student ratio

8. Environmental Health

- 8-11. Elevated blood lead levels in children
- 8-20. School policies to protect against environmental hazards
- 8-22. Lead-based paint testing

9. Family Planning

- 9-2. Birth spacing
- 9-7. Adolescent pregnancy
- 9-8. Abstinence before 15 years
- 9-9. Abstinence among adolescents aged 15 to 17 years
- 9-10. Pregnancy prevention and sexually transmitted disease protection
- 9-11. Pregnancy prevention education

13. HIV

- 13-17. Prenatally acquired HIV infection

14. Immunization and Infectious Diseases

- 14-1. Vaccine-preventable diseases
- 14-2. Hepatitis B in infants and young children
- 14-18. Antibiotics prescribed for ear infections
- 14-19. Antibiotics prescribed for colds
- 14-22. Universally recommended vaccination of children 19-35 months of age
- 14-23. Vaccination coverage for children in day care, kindergarten, and first grade
- 14-24. Fully immunized children 19-35 months
- 14-25. Providers who measure childhood vaccination coverage levels
- 14-26. State/community population-based immunization registries for children
- 14-27. Vaccination coverage among adolescents
- 14-30. Adverse events from vaccinations
- 14-31. Active surveillance for vaccine safety

15. Injury and Violence Prevention

- 15-1. Nonfatal head injuries
- 15-2. Nonfatal spinal cord injuries
- 15-3. Firearm-related injury deaths
- 15-4. Proper firearm storage in homes
- 15-5. Nonfatal firearm-related injuries
- 15-7. Nonfatal poisoning
- 15-8. Deaths from poisoning
- 15-9. Deaths from suffocation
- 15-10. Emergency department surveillance systems

- 15-11. Hospital discharge surveillance systems
- 15-12. Emergency department visits
- 15-19. Safety belts
- 15-20. Child restraints
- 15-23. Bicycle helmet use
- 15-24. Bicycle helmet laws
- 15-31. Injury protection in school sports
- 15-33. Maltreatment and maltreatment fatalities of children
- 15-38. Physical fighting among adolescents
- 15-39. Weapon carrying by adolescents on school property

18. Mental Health and Mental Disorders

- 18-2. Adolescent suicide attempts
- 18-7. Treatment for children with mental health problems
- 18-8. Juvenile justice facility screening
- 18-15. Eating disorder relapses

19. Nutrition and Overweight

- 19-3. Overweight or obesity in children and adolescents
- 19-4. Growth retardation in children
- 19-12. Iron deficiency in young children and in females of childbearing age
- 19-13. Anemia in low-income pregnant females
- 19-14. Iron deficiency in pregnant females
- 19-15. Meals and snacks at school

21. Oral Health

- 21-1. Dental caries experience
- 21-2. Untreated dental decay
- 21-8. Dental sealants
- 21-9. Community water fluoridation
- 21-10. Use of oral health care system
- 21-13. School-based health centers with oral health component
- 21-14. Health centers with oral health service components
- 21-15. Referral for cleft lip/palate
- 21-16. State-based surveillance system

22. Physical Activity and Fitness

- 22-6. Moderate physical activity in adolescents
- 22-7. Vigorous physical activity in adolescents
- 22-8. Physical education requirement in schools
- 22-9. Daily physical education in schools
- 22-10. Physical activity in physical education class
- 22-11. Television viewing
- 22-12. School physical activity facilities

24. Respiratory Diseases

- 24-1. Deaths from asthma
- 24-2. Hospitalizations for asthma
- 24-3. Hospital emergency department visits for asthma
- 24-5. School or work days lost

25. Sexually Transmitted Diseases

- 25-9. Congenital syphilis
- 25-10. Neonatal STDs
- 25-11. Responsible adolescent sexual behavior
- 25-12. Sexual behavior messages on television
- 25-14. Screening in youth detention facilities and jails
- 25-17. Screening of pregnant women

26. Substance Abuse

- 26-6. Adolescents riding with a driver who has been drinking
- 26-9. Substance-free youth
- 26-10. Adolescent and adult use of illicit substances
- 26-14. Steroid use among adolescents
- 26-15. Inhalant use among adolescents
- 26-16. Peer disapproval of substance abuse

26-17. Perception of risk associated with substance abuse

27. Tobacco Use

27-2. Adolescent tobacco use

27-3. Initiation of tobacco use

27-4. Age at first use of tobacco

27-6. Smoking cessation during pregnancy

27-7. Smoking cessation by adolescents

27-11. Smoke-free and tobacco-free schools

27-14. Enforcement of illegal tobacco sales to minors laws

27-15. Retail license suspension for sales to minors

27-17. Adolescent disapproval of smoking

28. Vision and Hearing

28-2. Vision screening for children

28-4. Impairment in children and adolescents

Terminology

(A listing of all abbreviations and acronyms used in this publication appears in Appendix K.)

Birth defect: An abnormality in structure, function, or body metabolism that is present at birth, such as cleft lip or palate, phenylketonuria, or sickle cell disease.

Breastfeeding: Exclusive use of human milk or use of human milk with a supplemental bottle of formula. "Exclusive breastfeeding" refers to the use of only human milk, supplemented by solid food when appropriate but not supplemented by formula.

Children with special health care needs: Children who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health care and related services of a type or amount beyond that required by children generally.

Congenital anomaly: See birth defect.

Developmental disabilities: A broad spectrum of impairments characterized by developmental delay or limitation or both in personal activity, such as mental retardation, cerebral palsy, epilepsy, hearing and other communication disorders,

and vision impairment. The more severe developmental disabilities require special interdisciplinary care.

Fetal alcohol syndrome

(FAS): A cluster of structural and functional abnormalities found in infants and children as a result of alcohol consumption by the mother during pregnancy and characterized by growth retardation, facial malformations, and central nervous system dysfunction.

Fetal death: The death of a fetus in utero after 20 weeks or more of gestation. The fetal death rate is the number of fetal deaths in a population divided by the total number of live births and fetal deaths in the same population during the same time period.

Eclampsia/Preeclampsia: A condition that occurs late in pregnancy, characterized by hypertension, edema, and proteinuria. When convulsions and coma are associated, it is called eclampsia.

Ectopic pregnancy: A gestation elsewhere than in the uterus, often occurring in the fallopian tube. An ectopic pregnancy cannot develop normally and causes fainting, abdominal pain, and vaginal bleeding.

Genetic disorders: The group of health conditions that result primarily from alterations in a gene or combination of genes.

Gestational trophoblastic disease: A type of cancer associated with pregnancy in which a grape-like mole develops in the womb.

Hypotonia: A condition of diminished tone of the skeletal muscles, with diminished resistance of muscles to passive stretching.

Infant death: Death of an infant less than 1 year old. Neonatal death is the death of an infant less than 28 days after birth; postneonatal death is the death of an infant between 28 days and 1 year after birth. The infant death rate is the number of deaths of infants less than 1 year old (obtained from death certificates) per 1,000 live births in a population (obtained from birth certificates).

Intrauterine growth retardation (IUGR): The failure of a fetus to maintain its expected growth potential at any stage of gestation. Infants with IUGR may be born at full term but are smaller than expected.

Intrapartum period: Period extending from the onset of

labor through the completion of delivery.

Level III hospital: A facility for high-risk deliveries and neonates that can provide care to very small infants, including mechanical ventilation and neonatal surgery and special care for transferred patients and for which a full-time neonatologist serves as the director.

Live birth: The complete expulsion or extraction from its mother of an infant, irrespective of the duration of pregnancy, which after such separation, breathes or shows any other evidence of life, such as the beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached. Each infant from such a birth is considered live born.

Low birth weight (LBW): Weight at birth of less than 2,500 grams (about 5.5 pounds).

Maternal death: Death of a woman while pregnant or within 42 days of the end of pregnancy, irrespective of the duration or site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes. The maternal death rate (also referred to as the maternal mortality ratio) represents the number of maternal deaths for every 100,000 live births.

Medical home: Medical care for infants and children that is accessible, continuous, comprehensive, family-centered, coordinated, and compassionate.

Neonatal period: The first 28 days of life.

Neural tube defects (NTDs): A set of birth defects that result from failure of the neural tube to close in utero. Two of the most common NTDs are anencephaly (absence of the majority of the brain) and spina bifida (incomplete development of the back and spine).

Occurrence: As the term is used in this chapter, occurrence is the incidence of new cases among livebirths per year that are caused primarily by prenatal factors. In the spina bifida and other neural tube defects objective, identification is in the first year of life, and occurrence is reported as the number of cases per 10,000 livebirths per year. In the fetal alcohol syndrome objective, some children who have the condition at birth are not identified until age 4 or 5 years; occurrence is reported as a number per 10,000 live births. In the developmental disabilities objective, children with specified conditions such as mental retardation are not always identified until about age 7 or 8 years even though the conditions are usually caused by prenatal events; occurrence in these objectives is reported as a number per 10,000 children aged 8 years.

Perinatal death: Includes fetal deaths after 28 weeks of gestation and infant deaths within the first 7 days of birth. This definition represents the standard definition promoted by the World Health Organization and is therefore useful for international comparisons.

Postneonatal period: The period from an infant's 29th

day of life until the first birthday.

Postpartum period: The 6-week period immediately following birth.

Preeclampsia: (see eclampsia)

Prenatal care: Pregnancy-related health care services provided to a woman between conception and delivery. The American College of Obstetricians and Gynecologists recommends at least 13 prenatal visits in a normal 9-month pregnancy: one each month for the first 28 weeks of pregnancy, one every 2 weeks until 36 weeks, and then weekly until birth.

Preterm birth: Birth occurring before 37 weeks of pregnancy.

Sudden infant death syndrome (SIDS): Sudden, unexplained death of an infant from an unknown cause.

Surfactant: A surface-active agent that prevents the lungs from filling with water by capillary action.

Synthetic surfactant: An artificial substance that prevents a newborn's lungs from filling with water.

Teratogenic: Causing malformations of an embryo or fetus.

Very low birth weight (VLBW): Weight at birth of less than 1,500 grams (about 3.3 pounds).

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